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ABSTRACT

A discussion of informed consent in research on children focuses on the history of informed consent and problems of obtaining informed consent from young children. It is argued that, in the past, researchers and research monitors have assumed that parents will act in the best interests of children participating in research and protect them from harm. However, the practice of using parents as proxy does not adequately meet the requirements for informed consent. While children may not be able to completely understand the research process and be truly informed, researchers believing in the value of informed consent and the rights of young children will take steps to help children be better informed subjects. Suggestions on how researchers can attend to the rights of young children are offered. Specifically, researchers must try to ensure that no harm comes to their subjects. They must explain the purposes and procedures of their study to young children. In conjunction with teachers, researchers should teach children what research is about. Researchers should be sensitive to children's needs and wishes in the research setting. It is concluded that the ethical treatment of subjects is always worth the extra effort. (RH)

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**A Case for Obtaining Informed Consent
From Young Children**

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Running Head: Informed Consent

ABSTRACT

Researchers of young children have historically relied on proxy consent from parents as a substitute for obtaining informed consent from children. However, proxy consent does not fully meet the requirements of informed consent. Because children are capable of giving a degree of informed consent, subject to developmental restrictions, researchers concerned with ethical treatment of young children can take steps to ensure that the rights of children are honored. Strategies researchers can use to help young children understand the research process and be better able to give informed consent are discussed.

Although most early childhood educators realize the importance of research to provide a base for practice, in the past the majority of early childhood educators have relied heavily on theories of practice. In a theory of practice, practitioner observations are used to construct the environment in a way that best meets the needs of the most children (Fein & Schwartz, 1982). However, it is becoming necessary to conduct research in early childhood settings to ensure the growth and further professionalization of the early childhood field (Bowman, 1986; Goffin, & Weikart, 1989).

The notion of NAEYC's developmentally appropriate practices (Bredekamp, 1988) provides an example of the state of early childhood education research. Although the practices are fairly well accepted, there is still little empirical evidence supporting the effectiveness of such practices (Kontos, 1989). Early childhood researchers are now beginning to produce more empirical research aimed at validating the beneficial effects of appropriate practices (e.g., Burts, Hart, Charlesworth, & Kirk, in press; Dunn, 1990; Hirsh-Pasek, Hyson, Rescorial, & Cone, 1989).

This is just an example of the challenges that researchers interested in early childhood must meet -- that of generating empirical evidence to support current practices. A few of the challenges are: developing more valid and reliable measures of quality of teaching and environment, separating the effects of

early childhood settings' content, activities, materials and teaching techniques on young children in order to determine the effects of child care and different curriculums, and determining reasons for variations in effects of early childhood educational experiences by child gender (Powell, 1987).

As researchers respond to such challenges by doing more valid and reliable research studies, young children are many times used as the primary research subjects. Several types of harm that participants may experience as a result of research participation include feelings of fear, anger, stress, and lowered self-esteem (Diener & Crandall, 1978). Researchers must always be conscious of the problems their study can create and make every effort to minimize or eliminate any harm to subjects. This is especially true when the subjects are young children and therefore, less powerful in research situations.

The purpose of this paper is to encourage researchers to proceed with the interests of young research subjects in mind. An in-depth discussion of informed consent in research will focus on the history of informed consent and problems of obtaining informed consent from young children. Suggestions of how researchers can attend to the rights of young children will also be discussed

Informed Consent and Young Children

For years researchers have faced the problem of obtaining

informed consent from young children. The most common solution has been to secure proxy consent from the parent(s) or guardian(s) of children they wish to study. One major concern with the sole use of proxy consent is that it does not fully meet the requirements of informed consent for young research subjects.

Since the Nuremberg trials after World War II, researchers have been required to obtain informed consent from all research participants. According to the Nuremberg Code,

"the person involved [as a research subject] should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice...; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision." (Keith-Speigel, 1983)

Informed consent is a necessary component of human research. It is necessary for the protection of the subject's welfare and for the maintenance of good subject-experimenter relationships (Diener & Crandall, 1978). However, it is a requirement that causes many problems for researchers of young children. According to many scientists, children cannot meet the requirements necessary for informed consent. The Division of Developmental Psychology of the American Psychological Association's Ethical Standards suggest that, "Because the young have less knowledge and less experience,

they also may be less able to evaluate what participation in research means" (American Psychological Association, 1968)

According to Keith-Spiegel (1983, see also Touliatos & Compton, 1983), the necessary elements of informed consent, (from the Department of Health, Education and Welfare, 1971 and Levine, 1975) include an understanding by the subject

- of the purpose and procedures of the study
- of all possible risks and benefits
- of why the person was selected as a potential participant
- of possible alternatives to the study
- that he/she may ask questions that will be answered by researchers or by a third-party
- that participation is absolutely voluntary and that the person may stop participating anytime during the study.

To meet the requirement of informed consent, all of these things must be understood by any human subject before consenting to participate in a study. The same requirements exist for young children who are subjects in a research project. For those with experience and knowledge of early childhood development the difficulty of obtaining informed consent from young children is evident. Children's limited experiences and developmental level make it difficult for them to understand long-term goals of research, the concept of risk, and the meaning of self-determination (Touliatos & Compton, 1983; Keith-Spiegel, 1983). Most importantly, the very basic notions of voluntary consent and freedom to withdraw are

difficult for young children to comprehend and to practice.

In the past, obtaining informed consent from parents has been sufficient when doing research with young children. The assumption of researchers and those who monitor researcher practices (i.e., university human subjects committees, government funding agencies) is that parents will act in the best interests of the children and protect them from harm (Touliatos, & Compton, 1983; Keith-Spiegel, 1983). While this assumption enables researchers to study children with parental consent, the practice of using parents as proxy does not actually meet the requirements for informed consent. Often, researchers do not make an effort to obtain consent from children. Concern with the rights of children calls the sufficiency of only obtaining parental consent into question.

Farson (1974) suggests that "rights cannot be withheld from the very young solely on the basis of age any more than they can be withheld from the very old who may be similarly incapacitated." In order to ensure that the children are not coerced into participating in the research, to the extent possible, they should give their own informed consent.

The problem with obtaining consent from children is that they may not be able to understand the research process and be truly informed. Yet if researchers believe in the value of informed consent and the rights of young children, they should take steps to help children be better informed research participants. In Farson's (1974) words, "The inability to

exercise one's rights at any age, old or young, should simply mean that even greater care must be taken by society to guarantee the protection of these rights." There are several ways researchers can help children give truly informed consent.

First, researchers must try to ensure that no harm comes to their subjects. They can do so by attending to the general components of ethical treatment. Most researchers are careful to meet those general requirements so they will not be discussed in detail. Highlights of some of Diener & Crandall's (1978) suggestions concerning ethical treatment of subjects can be found in Table I.

Table I about here

Second, researchers must explain the purposes and procedures of the study to young children. Of course, the developmental level of the subjects places limitations on the child's understanding. Infants and toddlers (birth-2 1/2) cannot give their consent. The child's cognitive and language limitations make it necessary for researchers to rely only on proxy consent from parents or legal guardians.

Preschool age children (3-6) can understand the basic components of research if the explanation is appropriate for their preoperational cognitive style. If researchers explain their study in "concrete terms, in relation to the child's

immediate situation and recent personal experiences," preschool children can understand the research and give informed consent (Touliatos & Compton, 1983, p. 288). For example, researchers interested in studying children's group behaviors may explain to their subjects that they want to watch and see how children act with each other in the sandbox.

School-age children (7-12) are capable of making decisions about research on their own. More than preschool children, a child this age can think logically, take another's perspective and understand consequences (to a certain extent). There is no reason researchers can't obtain informed consent from these children.

Third, researchers in conjunction with teachers should teach children what research is about. The scientific process is a concept young children can begin to learn early in their education. Additionally, children must become familiar with the ideas associated with informed consent before they are able to give informed consent. They need to understand that their participation is voluntary, that they have the right to withdraw, the risks of the research, and the study procedures (Diener & Crandall, 1978).

Researchers can help children understand some of those components of informed consent by letting participants observe other children participate in the research tasks so they can become familiar with the procedures of the research. They can arrange for a child to refuse to participate while the

participants are observing and then explain that it is alright to refuse. Researchers can help facilitate teachers' attempts to help children understand research by speaking to the children about the research process as a "guest speaker." They can also act as consultants, helping teachers initiate a teaching unit about research. Other strategies for helping children learn about research and informed consent can be found in Helling and Hughes (1990).

Fourth, researchers need to be sensitive to children's needs and wishes. Some children may explicitly refuse to participate or may fail to cooperate with researchers. In a case of refusal to participate the child's wishes should be and usually are honored. More of a problem for researchers is learning to be sensitive to other children who participate in research, not because they choose to, but because they may not be assertive enough to refuse, may want to please adults, or may be accustomed to following adult instructions without question.

Another area of concern is the situation when researchers fail to attend to a child's signals, insisting that children participate when they don't want to or that they continue when they want to stop. Also, researchers are sometimes less than honest with young children about the purpose or nature of research. This is seen in the often-used, often-misleading statement used by researchers to enlist children's participation, "Let's go play a game". Although fun, game-like

activities are sometimes involved, such statements fall short of informing the child of the true purpose of the activities.

If researchers are concerned about children's rights and want to conduct ethical research, they must be direct, honest, and clear in their directions to children. They must also be attentive to the subject's signals. If the child does not want to participate in the research or if the child wants to stop participating, the guidelines for informed consent are clear. The child must be allowed to refuse or to withdraw from the research. In the words of the American Psychological Association (1968), "No matter how young the subject, he [she] has rights that supersede the rights of the investigator...". Allowing children to refuse or to withdraw is understandably difficult for researchers to implement when they are justifiably concerned with sample size and missing data.

However, persistence and patience can often overcome the child's unwillingness to participate. If a child refuses to participate, it may be that the child is engaged in an intense play session in the classroom and would be more willing to participate at another time. Similarly, a child who wishes to stop participating in a research task may simply be tired and need a break. Research tasks are often inappropriately long or difficult for young children. A sensitive, ethical researcher may allow that child to stop participating, and then resume the activity when the child is willing without losing valuable data or subjects. A more thoughtful, consistent strategy for this

problem would be to divide one lengthy session into two or three shorter blocks of time.

Conclusion

Researchers need to respect the rights and choices of young children. Although attending to children's informed consent issues makes the already exacting task of research with young children more complicated, time-consuming, and difficult, there are also positive side-effects. Certainly a better understanding of the research process will help the children understand why researchers ask them to do research tasks. It may lead to more accurate data due to the children's increased understanding and respect for the research purpose and process. In addition, ethical treatment of subjects is always worth the extra effort. It can lead to greater respect for research, trust of researchers, and increased professionalization of the field (Diener & Crandall, 1978).

To further the research effort in early childhood research studies, the rights of all parties involved in the research process must be met. Diligent and responsible researchers will keep in mind the components of ethical treatment of young children. They will also make every attempt to ensure child subjects are truly informed, willing participants.

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Table I.

Components of Ethical Treatment in the Research Process
(From Diener & Crandall, 1978)

Privacy. Procedures maintaining confidentiality or anonymity must be maintained and explained to subjects.

Confidentiality: Keeping information about specific people from being known (i.e., keeping names of participants in a locked file cabinet).

Anonymity: Ensuring there is no way of knowing who the participants are.

Use of technological equipment. Subjects must be informed when equipment such as tape recorders, video cameras, and one-way mirrors are used.

Use of Test Data. The results of tests such as IQ tests or psychological tests must be kept confidential, used only for the specific purpose for which the test was designed and implemented.

Parental access: Parents may have access to test results, but only when accompanied by a verbal explanation.

Cost/Benefit Ratio. If the costs of the research project outweigh the benefits, the research must be cancelled.

Informed Consent. All potential participants of a research study must be solicited through informed consent procedures.
